## DEMYSTIFYING DISABILITY

**TOOLKIT SHEET** 

Understanding disability isn't a straightforward concept; it's like a puzzle with many pieces. it's a journey that may change over time, both physically and emotionally.



What resources and support networks can connect individuals with disabilities to in order to enhance their well-being and empowerment?

# SELF CHECK IN

#### **TOOLKIT SHEET**

### Understanding the caregiver's burden

The caregiver's burden is a term used to describe the physical, emotional, psychological, and financial challenges experienced by individuals who provide care for a loved one who is ill, disabled, elderly, or otherwise dependent on their assistance.

This burden can manifest in various ways and is influenced by the nature of the caregiving role, the health condition of the care recipient, and the resources available to the caregiver.

### What are the signs?

• Stigma

Seek Support

Groups

- Role Strain
- Physical Strain
- Uncertainty about the future
- Social Isolation
- Financial Pressure
- Emotional Distress

## LET'S CHECK IN!

What emotions do you often find yourself tangled in? What strategies can you use to prevent further "tangling"?

Dractice

Mindfulness

Stap

Stap

Stap

Practice

Stap

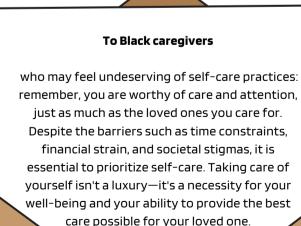
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## BUILDING YOUR UILLAGE

#### **TOOLKIT SHEET**



Your circle of support shouldn't adhere to a single template; it should be as diverse as the individuals within it. Each person you encounter, whether family, friends, or professionals, brings a unique set of qualities and perspectives that can contribute in various ways to your loved one's well-being.

### WHAT MAKES A HEALTHY VILLAGE?

- Diversity: Aim for diversity within your support circle to provide your loved one with a range of perspectives and experiences
  - **Commitment**: Choose individuals who are committed for the long term and willing to invest time and effort into supporting your loved one's growth and development
- **Communication:** Select people who are effective communicators and can maintain open and honest dialogue with you.
- Reliability & Commitment : Look for people who are dependable and consistent in their actions and commitments.
- Values Alignment: Never assume someone would go about caring for your loved one as you would.

## NEVER ASSUME

What makes a family? Our families are often the center of our circle of support but who we believe family should look like varies.

#### **ASKING FOR HELP**

#### Who to ask?

- Family Members
- Friends & Neighbors
- Community Organizations
- Therapists & Specialists
- Paid Caregivers/ Respite Care

Mixing up the types of support you utilize allows you to accommodate both you and your loved one's needs more effectively, preventing overreliance on any one avenue.

#### What to consider:

- Explore time constraints
- Never assume someone will or won't help you
- Open communication
- Consider barriers (e.g. do they have reliable transportation)

# LET'S BUILD!

Take a moment to think of your current circle of support. How do the people in your circle help you? Can you identify any gaps in your support needs?

ASK FOR

## NAVIGATING SYSTEMS & ADUOCACY

#### **TOOLKIT SHEET**

In a society where systemic inequalities persist, Black individuals with disabilities often face additional barriers and discrimination that can impact their access to necessary services and support. Therefore, empowering caregivers with advocacy skills is essential to ensure that their loved one receive the care, resources, and opportunities they deserve.



**Discrimination:** Black disabled children may be disproportionately placed in special education classes or face lower expectations from teachers due to stereotypes.



**Discrimination:** Healthcare providers may exhibit bias, leading to diagnostic delays, inadequate treatment, or dismissive attitudes



**Discrimination:** Black people with a disability may face social stigma, isolation, or exclusion from recreational activities and community events due to ableism and racial prejudice.

### WHAT YOU GAIN WHEN YOU ADVOCATE

 Empowerment: Self-advocacy gives you the power to voice your needs, preferences, and concerns
 effectively.

Assertiveness: Communicate your boundaries and rights without being aggressive or passive.

#### **ADVOCACY CHECKLIST**

#### Clear Communication

Prepare what you want to say ahead of time. Make sure it's clear and concise

O Document

Keep detailed records of meetings, conversations, and correspondence

• Collaborate with Professionals: Partner with healthcare professionals,

educators, and service providers to develop comprehensive care plans

#### Know Your Rights

Familiarize yourself with your loved one's rights and advocate for their full inclusion and access to services

Persist and Follow Up: Advocate persistently for necessary accommodations, services and supports and follow up regularly Access to Resources: Access the resources, support, and accommodations you need to thrive.

**Building Confidence:** Reinforce the idea that your voice matters and that you have the ability to affect change.

**Community Building**: Build networks and alliances with others who share similar goals and values.

**Conflict Resolution:** Teaches you how to navigate disagreements and negotiate solutions.

# **LET'S ADVOCATE!**

Think of a recent scenario where your advocacy style didn't accomplish what you set out to. Using the advocacy checklist, write what you would do differently

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